CLIMBING MOUNT EVEREST
CEREMONY CAPTURES JOY
HOLDING ON TO HOPE

LIFE WITH CANCER

Hollings Horizons
MUSC Hollings Cancer Center Magazine

Fall 2019
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HEADLINES

03 Highlights
Check out the latest patient resources and exciting happenings at MUSC Hollings Cancer Center.

FEATURES

06 Unmasking Skin Cancers
After seven surgeries, this Myrtle Beach professional golfer is on a mission to raise awareness about basal cell cancer.

12 Joyful Moments
This teenage couple celebrated their final moments together in a special ceremony.

16 Climbing Everest
Climber sets lofty goal of summiting Mount Everest to benefit cancer center.

22 Unusual Circumstances
In an odd turn of events, college student ends up saving life of retiree, and they form lifelong bond.

28 Head Shaving 101
Doctor turned cancer patient gives her tips on how to host a head shaving party.

34 Life After Cancer
Researcher studies how to improve the quality of life for cancer survivors and their caregivers.

38 Holding On To Hope
Patient with brain tumor explains how she deals with challenging side effects to live her best life.

42 Sarcoma Survivor’s Journey
Author and sarcoma advocate celebrates five years being cancer free.

RESEARCH

46 Highlights
This research roundup features exciting discoveries at Hollings.

48 Community Outreach
Researchers find ways to reach medically underserved populations, combat HPV-related cancers and tackle the cost of smoking on cancer care.

PHILANTHROPY

52 Highlights and Special Event
Discover how donors are making a difference in the quality of cancer care and about one of Hollings’ signature fundraising events – Gourmet and Grapes.

LOWVELO

54 Outdoor Bike Ride
See how these riders are changing how cancer research can be done.

On the Cover
Dr. Madelene Lewis gets her head shaved by hairdresser Cicily Hunt. Story, page 28
Commitment to Our Patients

Our fall issue of Hollings Horizons features how we here at the cancer center hope to make the lives of those who are touched by cancer easier. In these pages, you will read about how we are committed to being at the forefront of cancer research and getting transformational discoveries translated to the clinic. Committed to innovation, we look for ways we can change the face of a disease that adds an estimated 30,000 newly diagnosed cancer cases annually in our state.

As the only National Cancer Institute Designated Cancer Center in the state, we are tasked with knowing and addressing the cancer burden specific to our state. We do this through our research and clinical trials. We also do it through innovative community outreach, an important part of our mission. Take, for example, our $700,000 HPV initiative that we’ve undertaken to address the low HPV vaccination rate of our children in this state. Given there are six HPV-related cancers, this vaccination could prevent the more than 600 deaths occurring annually from HPV-related cancers. Prevention is at the forefront of cures.

This year, we launched an innovative outdoor bike ride called LOWVELO in which 100% of every rider-raised dollar goes to fund cancer research and accelerate life-saving research reaching the bedside of our patients. The ride has brought together hundreds of riders and volunteers all committed to this fight against cancer. You’ll read some of their stories here.

Speaking of which, I want to thank the patients and caregivers who bravely have shared their journeys in these pages. They are people like Dr. Madelene Lewis, featured on the cover, who is not only a physician here at Hollings but also a cancer patient. She explains how one of her toughest struggles was losing her hair and how she took a potentially traumatic experience and shaped it into a life-sustaining one.

It is through the sharing of our mission and our patient stories that we stand the best chance in this fight against cancer. Our invitation is to join us in the cause. We are stronger as a community finding tomorrow’s cancer advances today.

Best Wishes,

Gustavo Leone, Ph.D.
Director of MUSC Hollings Cancer Center
Clinical Trial Brings Prostate Cancer Patient Hope

When he found out that his prostate cancer was at a higher risk for recurrence, Ken Drachman enrolled in a clinical study led by Michael Lilly, M.D., a Hollings Cancer Center oncologist and researcher. The trial would help train his body to fight off prostate-specific antigen (PSA) cells.

“PROSTVAC is a poxvirus-based vaccine which is designed to stimulate the body’s immune system to attack cells that make PSA,” Lilly says. “The goal of the clinical trial is to see if patients receiving PROSTVAC, starting right after surgery, have a longer period of remission or disease control than matched patients who didn’t receive PROSTVAC.”

The low-toxicity vaccine currently is used in several ongoing studies, including the trial at the Hollings Cancer Center, and other studies at the National Cancer Institute. The vaccine is licensed by Bavarian Nordic Immunotherapeutics, a company based in Denmark.

Over the course of six months, Drachman was injected with seven shots of different vaccines to train the body to reject PSA. Since July 2016, PROSTVAC has enrolled 25 patients, each participating for two years. Drachman has completed the program.

“The happy report is my PSA has not gotten over .01,” Drachman says. “We’re very fortunate to have all of this here in Charleston.”
Hollings Cancer Center Lands Its Highest Score, NCI-Designation Renewal

Hollings Cancer Center landed its highest score yet in the renewal of its designation as a National Cancer Institute Cancer Center.

NCI-Designated Cancer Centers represent the top 4% of cancer centers in the United States. With this five-year renewal, Hollings is one of only 71 cancer centers in the U.S. with this prestigious status and the only such institution in South Carolina. Hollings has held this designation since 2009.

Gov. Henry McMaster underscored the importance for the state. “This is just one more example of the excellence that South Carolina produces. Congratulations are in order for MUSC and the Hollings Cancer Center for this impressive designation and for the important work that we know its scientists, doctors and researchers will continue to do there.”

Hollings Cancer Center Director Gustavo Leone, Ph.D., said the renewal affirms the cancer center’s strong research base and supports its mission to deliver cutting-edge treatments.

“Work at Hollings will lead to important advances in cancer research and clinical care. This designation will accelerate the speed by which we bring scientific and clinical discoveries to prevent and eradicate cancer in the state.”

Recommended Playlist

At Hollings Cancer Center, we believe in the holistic care of our patients. It’s why we offer yoga classes and art and music therapy as tools to help our patients cope. Here, Tammy Flovin, a board-certified music therapist in the Arts in Healing program at MUSC, shares songs on one of her favorite playlists to energize, promote mindfulness and decrease anxiety.

1. The Piano Guys: “A Thousand Years” – Christina Perri cover (4:31)
3. The Piano Guys: “Paradise” – Coldplay (Peponi) cover (4:25)
4. David Lanz: “Variations on a Theme” – from Pachelbel’s Canon in D Major (9:52)
5. David Lanz: “Cristofori’s Dream” (6:10)
6. Amavi Music: “Hallelujah” – Instrumental cover, piano, violin, cello (5:01)
8. Yuri Sazonoff: “Awakening Senses” (12:10)
9. Deuter: “Kindred Spirit” (8:19)
10. Eric Harringer & John Paul Lacey: “Cry of the Earth” (10:09)
T-VEC Offers Promising Treatment for Melanoma

T-VEC, also known as talimogene laherparepvec, is a type of oncolytic virus therapy. It is made with a form of the cold sore (herpes) virus that has been changed in the laboratory to infect and break down cancer cells without harming normal cells. It is injected directly into tumors in the skin and lymph nodes.

It’s a type of treatment Steven Fee learned about after being referred to surgical oncologist Andrea Abbott, M.D., at Hollings Cancer Center. He was relieved to hear her plan didn’t involve another surgery. He already had undergone three surgeries at other centers to treat melanoma tumors on his leg.

There will be an estimated 96,480 new cases of melanoma this year in the nation and an estimated 7,230 deaths, according to the American Cancer Society. The numbers don’t surprise Abbott, who specializes in melanoma treatment. The good news is that there are more therapies for patients.

“At this point in time, I’m the only provider who offers T-VEC here at MUSC and, to my knowledge, I’m the only provider in the state. I have patients who are traveling five-plus hours to come here for this treatment,” she says. “I have seen dramatic results for patients with melanoma with T-VEC treatment. To have this in my toolkit, to be able to offer it to patients, when surgery is not going to solve the disease, is very exciting to me.”

Survivors’ Fit Club

There’s nothing like a fun round of boxing to get rid of some stress. That’s just one of the activities participants in Survivors’ Fit Club get to try. This program, launched in February 2016 in collaboration with the MUSC Wellness Center, helps breast cancer survivors. The 10-week program focuses on exercise, nutrition and emotional wellness. The staff includes a registered dietitian, exercise physiologist, post-rehab exercise specialist, health coach, cognitive-behavioral therapy specialist and certified personal trainers – all available to participants interested in getting fit for life. Visit musc.co/fit-club for more information.

Surgical oncologist Dr. Andrea Abbott shares a moment with Steven Fee, one of her patients who received T-VEC therapy.
Some people get cancer, and no one ever knows. That’s the way they like to keep it.

For Hugh Royer, who lost a quarter of his cheek and his nose to a very common skin cancer, that was never an option. He learned that his face was his window to the world, affecting how people interacted with him.

Early in his treatment, he had people stop dead in their tracks in stores to stare openly at him. Some kids shied away from him. One half-drunk man leaving a bar even asked if he had gotten beaten up in a mixed-martial arts fight.

“No, just cancer,” Royer answered, silencing the man.

Becoming more of a hermit to avoid the embarrassing interactions, Royer struggled to find his bearings. Now, seven surgeries and 30 rounds of radiation later, the Myrtle Beach professional golfer is just grateful to be alive. And he’s a man on a mission to educate others in hopes they can learn from his cautionary tale.

Royer’s nightmare started with basal cell carcinoma, the most common form of skin cancer. People get it all the time. In the U.S. alone, an alarming 4 million cases are diagnosed each year. Most cases are curable and cause minimal damage. But not all, as Royer would learn.

He had a basal cell carcinoma removed from his nose in 2012 and got a recurrence treated in 2015. Then in 2016, a bump appeared on the side of his nose, and it kept growing. Three different doctors said it was nothing. But Royer kept seeking different opinions, finally finding a Myrtle Beach ear, nose and throat specialist who did a biopsy. Royer was diagnosed with basal cell carcinoma.

Royer was glad to get a diagnosis that made more sense for the spot on his face that just kept growing. He was referred to Hollings Cancer Center at the Medical University of South Carolina. “It comes down to that point where you know that you’ve got to go with your gut. You know something’s not right. It’s your body. You know what your body does and what it feels like. And it just didn’t feel right,” he recalls.

Hugh Royer and Dr. Evan Graboyes formed a strong bond during his extensive treatment.
“My advice now is don’t be afraid to upset that doctor to go get another opinion. Because if it comes back the same, then everybody’s correct, and it’s a win-win for everybody. But if it’s a different answer, then you need to find out exactly what’s going on. That’s kind of what happened to me, and it ended up saving my life.”

Meeting with specialists at Hollings, Royer learned that his tumor had grown, following along the pathway of a nerve. It had inched along and come within a centimeter of his brain. Scheduling his surgery in May 2018, doctors told him there was no time to waste, and treatment wouldn’t be easy.

Royer, typically talkative and energetic, remembers going home speechless. “I never said a word,” he recalls. “When I got home, I immediately took a shower. And I got in my pajamas, and I got in bed. The depression – I can’t tell you how bad it was. And then, at like 10:30 that night, my phone rang.”

Royer didn’t answer it. But his wife, Heather, did. It was Evan Graboyes, M.D., a head and neck oncologic and reconstructive surgeon and researcher in the Cancer Control Program at the Hollings Cancer Center, who had seen Royer earlier in the day. She put the phone on speaker and made her husband sit up and listen. The conversation would last over an hour.

“He talked me off the ledge and explained things to us to where, not only was it comforting, but it also helped us to understand what they were talking about,” he says. It wouldn’t be the last time a pep talk from Graboyes would be a vital lifeline. Royer recalls another time he came into his room as he was recovering from one of his first surgeries. “He walked in and sat on the bed and smiled at me and patted me on the leg. And I’m half out of it, but I’m looking at him, and he says, ‘This is going to be OK. We’re going to get it.’ And he got it. When you have a doctor that really cares about you, and shows you, that says a lot about what you’re trying to accomplish here at Hollings.”

The Back Nine
If there’s one thing that golf teaches you about life, it’s about having the right mindset to face tough challenges. Royer, known as “Little Hugh” in golfing circles, knows all about that. His face lights up when he talks about the game and the professional players he has been around all his life.

Royer excelled at Brookstone School and Columbus State University and was considered one of the best amateur golfers in Georgia history, eventually turning pro. He won four times on the Ben Hogan/Nike Tour, which is now the Korn Ferry Tour, and had three top-10 finishes on the PGA Tour. He is having to take it easy during his recovery, but he hopes to be part of the Champions Tour qualifying school this fall to prepare for the 2020 season.

Though he’s back to playing golf, his journey this past year has forever changed him. For one thing, it has led him to consider many on his MUSC Health care team as a part of his family, including two of his main providers, Graboyes and Samuel Oyer, M.D., a facial plastic and reconstructive surgeon. He jokes about how young they are, both under 40, but how their personalized way of approaching his care is reminiscent of “old-timey” country doctors.

“I’m so grateful because they literally saved me. Dr. Graboyes took my face apart, and Dr. Oyer put it back together. And they’ve been there for me to talk me
off the ledge. You don’t always find that in doctors. They’re young, but they get it. They are the ones who are going to change medicine.”

The trio joke together like they’ve known each other for years. Graboyes even FaceTimed Royer recently, when he turned 55, to wish him happy birthday. And it’s not just the care from Graboyes and Oyer for which he is thankful. There are the nurses and Anand Sharma, M.D., a radiation oncologist at Hollings, who did the 30 rounds of radiation. “It’s knowing exactly where to hit and what to hit and what to do because it is your face. And it’s pretty scary,” he says. “And it was pretty amazing.”

Zachary Soler, M.D., an otolaryngologist and specialist in sinonasal tumors, came on board to rebuild his right sinus and make sure he could still breathe out of that side of his nose. Royer says he’s grateful for how his doctors coordinated what was very complicated care throughout the process.

His professional team had to get creative. They ended up taking cartilage from an ear and rib, fat from his abdomen and fascia from his leg to rebuild his cheek and nose. They also performed two forehead flaps, a procedure that involves taking skin from the forehead with its own blood supply and attaching it to the nose to replace the missing skin. The flaps remain attached until the nose is fully healed.

“Cancer is scary for people, and then having a hole in your face is scary. And those two combined, I think, just magnify that challenge because no one thinks about it until you have a defect or a scar on your face. But that’s how we all recognize each other. That’s how we communicate with each other.”

- Dr. Samuel Oyer
Oyer says head and neck cancers pose special challenges for patients and require a multidisciplinary approach.

“Cancer is scary for people, and then having a hole in your face is scary. And those two combined, I think, just magnify that challenge because no one thinks about it until you have a defect or a scar on your face. But that’s how we all recognize each other. That’s how we communicate with each other. And you can’t cover that up, you know. It’s right there. It’s your billboard.”

With these kinds of reconstructions, the goal is not to make a person look better than he or she used to. “Rather, the goal is to be able to go to the grocery store and not have people ask you what happened to your face. You want to be able to go about your life and not have people pointing.” Oyer says, adding that in severe cases that is unfortunately not always attainable. “But that’s where we try to set our sights.”

The psychological care is just as important. Graboyes, who also is a researcher in Hollings Cancer Center’s Cancer Control Program, studies body image concerns in patients with head and neck cancers. It’s why he was part of a team of researchers to develop a new program called BRIGHT (Building a Renewed Image after Head and neck cancer Treatment) to help to address the psychological, emotional and social concerns of head and neck cancer patients suffering from body image disturbance.

Graboyes also is part of a multidisciplinary team of Hollings Cancer Center researchers who are developing:

• Better markers to predict which head and neck cancer survivors will suffer from body image concerns.

• Tools to measure body image concerns that are centered on the patient.

• New interventions to help to address body image concerns following treatment for head and neck cancer survivors.

Royer is a perfect example of why more support is needed, Graboyes says. Not only was he dealing with surgeries and dozens of appointments for his medical treatments, he also had the psychological distress of what cancer had done to his face.

Even though basal cell carcinoma generally is one of the most easily treated cancers, there are exceptions. “Sometimes, because patients and providers don’t take it seriously, it gets undertreated,” Graboyes says. “We see a lot that maybe didn’t get the most complete treatment the first time around, and then the cancer can come back in a much more aggressive manner. We also see cases where patients have ‘something’ taken off their faces and either someone didn’t tell them it was cancer or they didn’t have it tested for cancer.”

Oyer says it’s why he instructs patients to know their medical histories. They’ve had patients come in with partial facial paralyses that were thought to be Bell’s palsy. When Oyer asks if a patient has ever had a skin cancer, often the answer is yes. “The patient thinks the cancer was cleared, but it’s the sort of scenario where it gets into the nerve, and then tracks along the nerve. The nerves are like little highways for cancer sometimes, and there are a lot of nerves in the face. That’s when it can get tricky if it starts heading toward the brain,” he says.

“So just know your history. Know what you have and that this could come back later and be a more aggressive type of skin cancer.”

Oyer says he’s been amazed at Royer’s spirit.

“For me, it was a good reminder and an example of how to take a bad situation and make something good out of it. It is the lemonade out of lemons. Where some other person, most other people actually, would probably still be wallowing in some kind of ‘self-grief,’ he actually found a way to reinvent himself. He’s literally excited about his
opportunities moving forward and this whole new avenue that has opened up where he sees himself as an advocate rather than a victim.”

Graboyes agrees and is grateful that Royer dedicates a portion of his time to educating groups, particularly golfers and those who spend a lot of time outdoors. “We compliment Hugh for his persistence; it’s the reason he’s alive. The advocacy work he has done since his diagnosis is truly inspirational. We hope his story empowers other patients to notice if there is something not right on their body, and go and get it checked out and properly evaluated.”

Moving On
It’s not unusual for Royer to take the stage these days, not so much to share his golfing triumphs as to encourage others. He still likes to joke and cut up. That hasn’t changed. He does find he’s more humble and emotional, though. Cancer can do that – strip a man down to the basics, he says.

“I’m looking down at the grass. I’m not looking up at the roots. And that’s the way that I take it – day to day. Being thankful that I’m above ground, and I can live life.”

- Hugh Royer

One poignant memory he holds dear involves an evening after one of his major surgeries when he woke up to see Abbey, who had taken some time off from school to be with him, draped at the bottom of his bed, sleeping.

“You know, when you wake up in the middle of the night in the hospital and your 16-year-old is sitting on the edge of your bed and you catch her blotting your face,” he says, stopping a moment to compose himself before continuing. “What 16-year-old does that? It just makes you appreciate life, appreciate your family. It’s brought us all, even though we’re close, that much closer.”

Royer has noticed how often that, after he’s delivered a talk about his story, people will come up to him to thank him and share their journeys.

“That makes me feel like I’m doing some good. And if you can help people, and you help save lives, I mean, that’s what it’s all about. I always thought God put me on this earth to play golf, but I think it was to go through this and to help people. I’m going to make the most of life.”
TEENAGE COUPLE CELEBRATES FINAL MOMENTS IN A SPECIAL CEREMONY
In just moments, Hollings Cancer Center inpatient nurses transformed the area. They used the pink plastic ice buckets for patients to chill the sparkling cider. A hospital cart became a catering table. A sheet, a tablecloth. And somehow a white, scalloped two-tiered cake miraculously appeared next to festive gold napkins.

It would become a day Justice Dunlap, 18, would later describe as perfect.

It was thought the teenagers would have their commitment ceremony near the exercise bikes in the waiting area on the seventh floor of the Ashley River Tower (ART) at the Medical University of South Carolina. However, Carrie Moore, unit nurse manager of the HOPE unit or the Hematologic Oncologic Protective Environment, would have none of that. She and other nurses set up the space to showcase the view of the Ashley River, arranging an aisle and seating for 25 guests.

Moore found out she had a special skill. Deejaying. She cued up the song that patient Eric Mason wanted for Justice as she walked down the aisle: John Mayer’s, “Slow Dancing in a Burning Room.” It’s not the typical song to walk down the aisle, but then these were unusual circumstances.

Eric, 19, knew time was of the essence. The moment was everything. During the past year, he had spent a lot of time with the staff on ART – 7W to be treated for aggressive lymphoma. When he relapsed after a stem cell transplant, his treatment transitioned to comfort care.

Moore says everyone grew to love him. “He was kind and generous and had a wonderful strength during even the toughest times of his treatment.”

When the staff learned the one remaining item on his bucket list was to show Justice how much he loved her, the team sprang into action. They called Hannah Coyne, the palliative care chaplain who had spent time with Eric. She already knew of his eloquence, his generous spirit and his care and concern for his family and friends.
Every single moment is important, even if it’s a bad moment.”

- Justice Dunlap

She came to see what she could do, discovering it was really important to Eric to be able to share his love and commitment to Justice in a spiritual ritual “in God’s eyes” before he died. Could Coyne help him? Of course, she could. They got to planning.

It was Thursday evening, March 14. The wedding would be the next day - a balmy spring afternoon affair. All the staff bonded together to do their parts to pull it off. Honored to officiate the ceremony, Coyne says it was a really joyful occasion in the midst of a lot of sadness.

“This spiritual ritual, looking out over the Charleston Harbor, was a reminder to everyone present that life is for living — to the end and to the fullest.”

Coyne took it all in. Eric decked out in all black with the pop of white of his bowtie. Best yet, the staff had worked to get the right mix of pain medications, so he was able to walk and be free of all his IV lines. She got a glimpse of the young man before he got sick.

“I believe it’s really important for our patients’ dignity. It’s also a good reminder for us as caregivers that each of our patients has a life and a story before ever stepping into our doors, and part of our job is to honor that.”

And honor it they did. Ask any guest what their favorite moment was, and the answers pour out.

For Coyne it was the “holy moment” of watching the extra long hugs that Eric and Justice shared with their parents after the ceremony. It was saying a prayer of blessing over Eric and Justice at the end of the ceremony to commend them to God’s continued care, in life and in death.

For Moore, it was getting to see the couple cut the cake and smash white icing into each other’s faces – a cake purchased by one of the first nurses to be involved with his care, Kate Hall.

“It was smiles. It was strength. It was ...” Moore pauses, searching for just the right word. “Love.”

The ceremony opened a moment to see Eric in a new light as if he weren’t sick. “He was Eric during that time. Moments like this not only make you a better health care provider, they make you a better human being.”

Eric and Justice enjoy a fun moment at the beach.
Moore says it was amazing to see how all the nurses, doctors and staff could pull together such a special event in a short time.

Justice says that she’s so thankful to the staff, some of whom even came in on their day off to make the ceremony perfect. The outpouring was, in part, a testament to Eric’s caring nature. He touched people in so many ways, and at the end, they were there for him. Everything just fell into place. Justice’s mother had the perfect lace dress she could borrow. His aunt crafted a homemade bow. The cake was beautiful. “It was more than I ever thought it could be. They made the day magical.”

The best moment for her: the kiss and seeing Eric so ecstatically happy.

Justice had popped the question just days before. “I asked him if he wanted to do this before it was too late. We had known we wanted to be together in the eyes of God for a long time.”

Justice says she will always treasure the memory of how happy he was that day. It comforts her as she now grieves his loss. He died March 18, the Monday after their ceremony.

The memories keep playing in her head. There was the first time she met him through mutual friends on Facebook. When he told her she had the nicest smile. They talked every day after that until meeting in person in January of 2017 at Surfside Beach. The day was so blustery and cold, they had to bundle up to withstand it. Conversation flowed easily, and they laughed in awe as a dolphin surfaced close to them. It was as if they had always known one another. They were inseparable after that.

When she got the call a year later that he was sick, it never occurred to her to break up. They liked the same type of music and, more importantly, had the same sense of humor. “We were perfect together. He was my other half.”

Justice says she’s forever changed by the experience. She’s considering becoming a pharmacist to help others, but for now, she’s taking time off to grieve and honor their memories.

Grateful to all the staff who became part of their extended family, Justice can tell she’s a stronger person now. She’ll always hold in her heart Eric’s memories and values. She says he was the most caring and selfless person she’s ever met, even when he was in the most pain of his life. He wanted everyone else to be happy.

Justice sees life in a whole different way. “Every single moment is important, even if it’s a bad moment.”
Climber Cokie Berenyi sets a lofty goal of summiting Mount Everest to benefit Hollings Cancer Center.
If there’s one life lesson Cokie Berenyi has learned, it’s that mountains can lie.

“You look up at the summit, and my brain and heart tell me no way. There’s no way I can make it to the top. And then I start to climb, and I remember—mountains lie. It’s a great life lesson, too,” she says, recalling hiking Mount Kilimanjaro with her daughter, who at the time was the youngest American female to make the summit. Her favorite moment happened on day four, which is one of the harder days of the 6-day ascent other than summit day.

Her daughter, Helen, swept ahead of her on the path at the end of a tough 10-hour day hike. Stepping over a little stream, Berenyi paused and looked at her daughter.

“I just teared up. It was at that moment that I knew she had the strength, physically and mentally, to summit. I was unsure of the power and strength of a 9-year-old. She was just a week shy of her 10th birthday.”

It’s a story Berenyi, who has two asset management companies and a financial consulting practice, has seen repeated over and over, whether conducting financial consulting or summiting alpine peaks. Small, ordinary steps can lead to extraordinary gains. It’s why she’s calling her campaign to summit Mt. Everest in 2020: Everyday Everest.

Along the way she’ll be raising funds for cancer research, prevention and awareness at Hollings Cancer Center at the Medical University of South Carolina. She realizes finding cures for cancer may seem unobtainable, just as scaling Mt. Everest does. “But it can be done—one dollar at a time.”

Berenyi acknowledges the climb is risky.

“With the irresponsible perspective that I may depart this Earth and leave my two children behind, this climb has to be about something bigger than myself. It just has to be. If there’s a way that I can impact more, as opposed to me just putting another notch in my Seven Summits belt, that’s what I want to do. I want to have more impact, whether it’s raising awareness or getting $1 closer to a cure or $1 closer to supporting more cutting-edge research.”
Helen of Troy

Just coming down the dirt drive to Berenyi’s house, it’s obvious the place has its own distinct playful style. The first clue are goats that have climbed on top of their little barns, curiously eyeing any newcomers coming onto the 40-acre farm in Awendaw. Past the goats is a beautiful Bohemian-style farmhouse framed by two silos.

In the top of one of the silos is her office. Dropping down the circular stairway is her meditation station, piled high with cushions and gobs of meaningful stuff that screams for her time. “I am not your consummate teacher of how to meditate. I do it all wrong,” she says, adding it’s not unusual to for her to tote a large mug of coffee into the space.

Drop down one more level to the ground floor, and there is her gym. The three levels are symbolic of how she tries to balance her life, prioritizing what’s important to her; spiritually, physically and financially. It’s what helps the mother of two, book author, founder of two non-profits, including She CLIMBS, and entrepreneur to remain focused on her goals. She’s quick to point out the silo is a small percentage of her home, her farm. Family is first. Cokie’s parents have lived on the farm since 2003.

On the wall in her living room is a picture of Helen of Troy by Molly B. Right, a local artist who specializes in oversized mosaic-like portraits made from vintage bottle caps. Berenyi loves it for both the art and the subject matter. “Helen of Troy is my hero. She, for me, epitomizes what I think is the elusive dichotomy in a woman between strong and beautiful. I think she did both. She nailed it.”

She didn’t always love her given name – Helen. She adopted the nickname “Cokie” in 2000 when Helen Coker married and became Helen Berenyi. “Cokie Coker was too bold even for me,” she says, laughing. Her oldest daughter, Helen Simmons, is seventh in a line of women stretching back to the 1800s who have held the name Helen. Her grandmother also was a Helen and died of colon cancer, and her grandmother’s daughter, Berenyi’s aunt, also was a Helen and died four years ago of ovarian cancer.

Berenyi says it’s one reason she serves on the Hollings Cancer Center Advisory Council and why she was drawn to dedicate this Everest summit campaign to fundraise to fight cancer.

“My Aunt (Helen) Rhett and I were very close. I’m Helen number six and then my oldest daughter, Helen Simmons, is number seven.”

Given the amazing advances made in cancer care, she wonders how that might have affected her friends and relatives who have been touched by cancer. She is hopeful for how the money she’ll raise through her climb will save lives in the future.

“The HPV vaccine that prevents six cancers and breast cancer awareness is huge. I mean, I know that my grandmother and my aunt would have lived longer, based on preventive screening alone, and perhaps not died of cancer at all had they lived in a different time, so I’d like to participate in that and not just be a passenger.”
Alpine Summits

Before 2003, the most hiking Berenyi had done was casual day hikes. Alpine climbing wasn’t even on her radar.

What was on her mind was racing into Magnolia Plantation where she was late for a Perfect Day workshop her life coach had asked her to attend. She worried how she would ever get in the right mindset to do a Perfect Day writing exercise. “I was like just checking boxes. I showed up fine. Check. She asked me to do it, and I’m doing it,” she recalls.

“I couldn’t believe I set an entire day aside, a non-revenue generating one, and I didn’t have two nickels to rub together. But somehow, I got into the space and wrote my perfect day. And it had me climbing the Seven Summits of the world, with three boys and running a nonprofit called She CLIMBS.”

While the boys turned out to be two daughters and two stepdaughters for her, the rest came true. Even though she had little experience with the outdoors except hunting with her dad, she began learning what was involved with alpine climbing and tackling the peaks. The life-coaching writing exercise so changed her life, she wrote a book titled Perfect Day and dedicated it to her mentor, Claire Stuhr, who died in 2006 after a long battle with breast cancer.

Now climbing is in her blood, and she can’t imagine it not being part of her life. She has climbed Mount Elbrus in Russia, Aconcagua in Argentina, Kilimanjaro in Tanzania and last summer, her toughest challenge, Denali in Alaska.

“There is nothing in the world like waking up to a sunrise, before the day starts, but I can’t do that in everyday life. I really have to have a motivator. But put that on steroids when you’re climbing. Waking up to a sunrise, and it’s actually below you, and you’re on a mountain, it’s just the most magical thing ever. And that is why I alpine climb.”

- Cokie Berenyi
My purpose in life is to impact women to elevate themselves in whatever way they can, and if that’s in a way in which they take care of themselves physically and preventatively, it all goes together."

- Cokie Berenyi

The other part for Berenyi, 46, is an existential aspect of getting a feeling of how big the universe is and that she’s just this blip of existence. “I have this Helen of Troy premonition that maybe I’m going to die at 50 — and I’d rather die on a mountain for a cause than of cancer or in my car in some tragic accident. But it’s a blessing because it makes me, as egomaniacal as it may sound, to just live every day as if it could be my last. I just make it all happen every day. It has been a positive mindset for motherhood — for giving them roots and preparing their wings as if I may not be here tomorrow. We’re all mortal after all.”

Berenyi pauses and smiles. “Maybe the simple answer is I get bored really easily, and I’m an adrenaline junkie. Maybe it’s just in my DNA, to live this life as full as I can.”

Regardless, she feels compelled to make the climb in May 2020. The big difference for her this time is that she can hopefully use her experience to impact others, particularly women, to get them to reset their lens and value self-care. She hopes her blogs and speaking engagements may inspire others to get that mammogram or adopt a healthier lifestyle or support cancer research.

“My purpose in life is to impact women to elevate themselves in whatever way they can, and if that’s in a way in which they take care of themselves physically and preventatively, it all goes together. I don’t want another Helen dying from cancer. I don’t want another friend, family member or person I don’t even know to lose one day on this extraordinary Earth because they didn’t take preventive measures against cancer.”

She’s glad her Everest climb may help elevate the cause, while it keeps her focused on how she becomes her best self.

“It just really fits my life,” she says of climbing. “It keeps me active all year long, and you go to amazing locales. You’re every day thinking about health and wellness, and it helps put that lens on it that gives reason and purpose to it for me,” she says. “So why do I exercise and eat well and take care of myself? Because I have a mountain to climb.”
Berenyi is shown here in her climb to the top of Mount Denali in Alaska in June of 2018.
Ben Hagood and Thomas Hayes (right) meet for the first time at the Charleston International Airport on May 10 of this year.
It’s odd how fate works. Four years ago, Charleston lawyer Ben Hagood was planning a dream vacation – a sailboat trip catching breezes in the Caribbean. Meanwhile, Thomas Hayes was looking forward to graduating from high school in his hometown in Kentucky.

The two, about 40 years apart in age, knew nothing about each other. They didn’t know they shared a strong Christian faith, for example, or had similar senses of humor. They didn’t know that if they met, they’d get along famously.

At that time, Hagood was enjoying life with his wife and two daughters. Hayes was enjoying life as a teenager anticipating high school graduation. He was eating lunch with his friends as they shared plans for the summer. An announcement was made that anyone 18 and older could come and be swabbed to be a potential stem cell donor. Hayes, who had just turned 18, debated going. He came close to opting out.

“It was lucky that it was that day, because if it was the day before, I never would have had this opportunity. And when we were all sitting around at lunch, and they called everyone to go up, I debated it for a second because I thought this will never happen. But I said if I have the chance to save someone’s life, I might as well take the time. And I got swabbed.”

Fast forward two years. It was five days before Hagood would leave for his trip of a lifetime. Hagood, who had had multiple myeloma, had been in remission for about six years. He debated canceling his routine check with Robert Stuart, M.D., an oncologist at Hollings Cancer Center, who specializes in blood cancers. He was excited and had a million details to arrange to be ready for his trip.

In the end, he kept his appointment. Unfortunately, the visit didn’t go as usual. Stuart told him he didn’t like the blood results, and he would be rerunning some tests. He’d call him in the morning.

Hagood tried to shift the worry and asked for prayer the next morning in his Bible study group. Shortly afterward, he got the call. “I think you better come in,” Stuart told him.

“Am I going sailing?” Hagood asked.

“No, you’re not.”
Hagood reeled from the bombshell. Knowing Stuart’s an expert in this area, he didn’t argue. He came in for a bone marrow biopsy and got the confirmation that not only did he have B cell acute lymphoblastic leukemia (ALL), but also he was very sick. He had 10 medications to pick up from the drugstore on the way home. His wife was traveling overseas, and he didn’t want to ruin her trip, so he decided not to tell her.

He unpacked his bags and went to get chemotherapy ports installed in his chest. "That was a lonely moment. I’ll be honest with you.”

Hagood learned that the acute leukemia was very different than the multiple myeloma he had had earlier. “It moves very fast. My bone marrow was clear a year earlier… But when Dr. Stuart got the bone marrow biopsy and the blood, the full blood test workup, I had something like 90% of leukemia blast cells in my blood and my bone marrow, so 90% of my system was diseased.”

Stuart didn’t share at the time how serious it was. Hagood could tell, though, that his daughter Nancy, a medical student who at the time was doing her rotation on the floor where he would be treated, knew. Hagood would later find out that if he had skipped his appointment and gone sailing without getting the proper treatment, he could have been dead within two weeks.

“So that thing was moving that fast. And, you know, I think about the timing of it all. How horrible was that? That it happened right before the sailing trip. But then you know how blessed I am that I got to have that blood test right before I went, and this thing got caught.”
Blood Connection

Stuart worked to get Hagood’s cancer in check and buy him time until a stem cell transplant could be arranged. The beauty of that transplant, if successful, is that it would be a double cure, both for the multiple myeloma in remission as well as the B cell ALL diagnosis.

Hagood, who has three brothers, figured someone in his family would be a match. “I was told by Dr. Stuart and the coordinator that my brothers were my best likelihood of a match, so they worked up my brothers first.”

It turned out that not one was a match, but there were more than 100 people in the database who were a full match, something he came to realize later was quite unusual. The search to find the youngest, best match led to a college student at Ohio University in Athens, Ohio, who hailed from Kentucky.

Hayes was on vacation when he got the call that he was a match. “I kind of forgot about it for two years. Two years later, I was sitting on my couch, and I get a call from a New York number. I’m thinking I don’t know anyone in New York, and for some reason, I decided to pick it up.”

He learned he’d been identified as a potential match for a patient with leukemia and was asked if he’d be willing to submit a blood sample, which he did. About a month later, he was told he was a perfect match and asked to come to Washington, D.C., to undergo some tests.

“A week later, on August 2 of 2017, I donated my cells, and one day later, they were here in Charleston,” Hayes says. “It felt surreal, because I remember when I first had that initial screening that they said one in 750 people get a call, so I was thinking this will never happen to me. And when it did happen to me, the guy kind of went over that sometimes people aren’t willing to do it.”

Though his mom was nervous and wanted more details, Hayes had a sense of peace about it. “I thought I have this surreal opportunity to be able to save someone’s life. It’s worth a little discomfort that I’ll have to go through to get the chance to do it. It was an amazing opportunity. It’s a feeling that I have the unique chance to feel, and I’m glad I did.”

Hayes did a nonsurgical donation, which he thought would be the smoother of the two options. He went to Washington, D.C., and was hooked up to an IV for six hours. Other than fatigue the next day, Hayes says it wasn’t that bad.

During the procedure, blood goes from one IV site into a machine where the white blood cells and stem cells are separated (by centrifugation) from the other blood cells and shunted into a bag. The other blood components, such as the red cells, platelets and most of the plasma, are returned to the donor through another IV site. Hayes says the worst part for him was having to sit for six straight hours. Asked if he’d do it again, he smiles. “Absolutely.”

Want to Help?

With their gift in 1986, the Oliver S. and Jennie R. Donaldson Charitable Trust made it possible for Hollings Cancer Center to establish a bone marrow transplantation program. Thirty-three years later, our award-winning BMT program is the largest and most comprehensive in South Carolina. Now we are looking for support in building the future home of this program — The Robert K. Stuart, M.D. Blood and Marrow Transplant Center. With your help, this state-of-the-art center will allow most patients to be moved into an outpatient setting — the new standard at top hospitals around the country. It will also provide the necessary infrastructure and resources to substantially grow our program, increasing transplant services by over 60%. Only through philanthropy are projects like these made possible. Make your gift to the Robert K. Stuart BMT Outpatient Clinic fund today and help us shape the future of the BMT program: musc.co/hcc-development.
Hagood was drawn to the piece of art, “Recovery Stroke,” while being treated at Hollings, and knew he wanted to share its meaning with Hayes if he ever met him.
Donor Reunion

In the lobby of Hollings Cancer Center is a giant sculpture of a wing. The artwork by Grainger McKoy is called “Recovery Stroke.” It’s a place Hagood, who responded well to his transplant, knew he wanted to go if and when he ever got to meet and thank Hayes.

Not everyone meets their donor, as there’s a year wait and both parties have to agree. During that time, Hagood couldn’t shake a need to thank his donor, though, and he decided he would try to reach out to the Be The Match program to see if his donor was willing.

Hayes was. They began corresponding and instantly bonded. On May 10 this year, they met in person. Hayes flew into Charleston with his mom and was met by Hagood and his family. As they toured Hollings Cancer Center and met the staff involved in Hagood’s treatment, there were tears and hugs all around.

Hayood, as he’d hoped, got to stop with Hayes in front of the sculpture. Drawn to the sculpture because it symbolizes the wing at the weakest part of the flight stroke, Hagood says it captures where he was before he got Hayes’ life-saving transfusion. The wing position produces neither lift nor forward momentum, but it has to happen to prep the power stroke to propel the bird forward.

Hayes helped him with his recovery stroke, and in the process, became a lifelong friend, Hagood says. “My daughter said that it was kind of like Dad’s long lost son is coming home. And yeah, I mean, it’s just somebody I have a blood connection with in an extraordinary way. It’s someone who has helped give me the gift of new life. I was just really excited to see him and thank him in person.”

Hayes, now 22 and a senior in college, feels the same way. They discovered they share the same Christian foundation and faith. “Growing up, it’s what I was taught. It’s where a lot of my morals have come from,” says Hayes.

“I’ve learned through the Christian faith to do unto others as they would do unto you. And if I was in his situation, sitting in his shoes, and there was someone with the opportunity to save my life, I would certainly want that to happen. So my faith really kind of pushed me to do this and gave me the moral background that I needed to make a decision like this.”

Hayood says he knows he’s lucky. Not everyone finds a match. He and Hayes hope their story will encourage others to get on the registry. For his part, he knows Hayes was meant to be in his life. There are too many intertwining links in their stories to be just fate. “It’s a God thing,” he says. “There are coincidences too great to be random.”

Hayes’ maternal grandfather was a close friend of former MUSC President James B. Edwards, who gave Stuart the approval to perform the first bone marrow transplant in the state 32 years ago. His paternal grandfather died of leukemia, something he didn’t know until he became a donor.

Hayood says he’ll be forever thankful to Hayes. “I think it’s from the divine that gives us all a desire to want to help other people. And I think that’s what motivated Thomas, originally, when he had the opportunity to go in the registry. But how extraordinary for him at age 20 to be part of this amazing medical process where he’s actually helped save my life.”

Hayes says he loves Charleston and feels a part of the Hagood family now. “I mean, there’s this connection that you just can’t fake. This is something that’s real and something that’s special between two people. I think we’ll stay friends for the rest of our lives.”
It’s cancer,” the doctor said. A whirlwind ensued, and within the next two weeks, I was notified by oncology that my aggressive form of breast cancer would be best treated with chemotherapy. I was anxious about what would happen to my body. “Chemo” was something I needed, but at what cost? As I read through the list of potential side effects, one stuck out in particular, alopecia, which meant I would likely lose my hair. Luckily, it ended up proving better than the dreaded scenarios playing out in my head.

After week five of my weekly treatments, the hair loss began. My long, thick mane of blonde hair started to fall out. At first, it was a small amount in my hairbrush. Then it was covering the shower drain. Within two weeks, handfuls of hair were coming out daily. Looking in the mirror was a constant reminder that my hair was visibly thinning and my scalp was slowly becoming more visible.

Initially, I was able to keep my cancer diagnosis to my closest friends and family; however, after losing my hair, I knew my diagnosis could no longer be concealed. Many people told me "It’s just hair, and it will grow back” and "you got this,” both true, but neither made losing a part of me any easier. As I contemplated how to handle this portion of my journey, I made a conscious decision to turn this into a positive transformation.

Dr. Madelene Lewis joined many close friends and family members who shaved their heads or added pink hair extensions.

"I

HEAD SHAVING

101

TAKING THE PLUNGE WITH FRIENDS AND FAMILY CAN BE A SUPPORTIVE, MEMORABLE EVENT

Dr. Madelene Lewis // MUSC Health Radiologist
Dr. Lewis hugs her son Isaac.
So, I decided to take my hair loss into my own hands and celebrate the fact the chemotherapy was working. What better way to celebrate than hosting a head shaving party! While this type of celebration isn’t for everyone, it certainly helped me cope with one of my early struggles and turned it into a favorable memory. I still look back on my head shaving party with the happiest of memories. In a tumultuous time, I finally felt in control. When asked what we did to make this event a success, my husband and I came up with some of our tips and considerations for hosting your own head shaving party.

**Timing**

Picking the date is tricky as everyone loses hair at a different rate and at a different time in their treatments. Therefore, it can be difficult to figure out when is the right time to take the plunge. I had significant thinning, so I ended up choosing a date around the time when my hair loss was getting unmanageable. We sent out invites to attendees a week in advance, and to our delight, we had great response.

**Location**

Somewhere comfortable! Pick a barber shop or hair salon if possible. We opted to have the event somewhere other than our house for several reasons. First, there is extra stress (in an already stressful time) prepping the house for guests, not to mention the clean up afterward. Head shaving can be messy (especially for large groups). We also didn’t want our guests to feel pressure to bring supplies (food, gifts, shavers, etc.) or feel intrusive. We privately asked the owner of our boys’ barber shop, and she graciously offered to host. As we approached the actual event date, we firmed up a guest list, and that allowed them to prep as well. LowCountry Barbershop graciously opened their doors to us on a Sunday morning, and three of their best ladies volunteered to come in on their days off to participate in our event.

**Decor/Food**

Keep it simple and easy. We assigned one person for decor and one for nourishment. Since we had a morning shave, we opted for pink donuts, hot coffee, orange juice and some champagne (as it was a celebration!). We had breast cancer awareness treats for our guests as well. Wrist bands, necklaces and knee-high socks were a hit with the kids. Pins and pink hair extensions were favorites with the ladies not joining the group getting shorn.

**The Shaving**

We encouraged anyone else who wanted to get their head shaved to sign up. I had no choice in losing my hair; however, I was absolutely blown away by the number of family and friends who willingly chose to shave their heads with me. I decided to go first and kick it off. As a mother, it was empowering to have my boys watch me shave part of my own head. It wasn’t a shock to them and gave us all a sense of control. My husband and three boys followed. All had close friends who came and shaved to support them as well. Finally, our last surprise for the
group was a charitable donation in honor of each of the 20 heads shaved that day.

Document
This was a momentous day! Mine was full of laughter and love. A wonderful friend took photographs of the event for us. We often look back at these photos with fond memories. Writing about your experience also allows you to relive the thoughts and emotions of the event weeks, months and even years later.

#Baldisbeautiful
Consider how you want to embrace your baldness. It is helpful to think about what you want and have everything ready for after the shave.

Some love a wig. You can get all colors, shapes and sizes. If you plan ahead, you can even use your own hair. As it was summertime in Charleston, I opted not to get a wig and instead stocked up on an awesome collection of scarves, hats and statement earrings. Keep an open mind and try new things. My sisters scoured the Internet and their local shops, finding me some head covers I initially would have never chosen, but many quickly became my favorites. Indoors and at nighttime, I remember being very cold, so I certainly recommend a soft, warm fuzzy cotton hat as well.

To be honest, initially I wondered if I was making the correct decision. I thought about canceling, having my husband turn the car around and just letting my hair keep falling out slowly over agonizing weeks. I was nervous how I would feel with people watching me undergo something very personal. Once I arrived at the head shaving event and saw my friends and family, I was uplifted by all their love and support. By embracing my baldness, I actually became more comfortable and confident than I had ever suspected I could be. It was amazing to have so many others be a part of this celebration, and I’m appreciative of their love and kindness.

“Once I arrived at the head shaving event and saw my friends and family, I was uplifted by all their love and support. By embracing my baldness, I actually became more comfortable and confident than I had ever suspected I could be.”

- Dr. Madelene Lewis
Cancer often steals the show from other medical conditions patients have, potentially setting patients up for poorer outcomes because their primary health needs get neglected.

No one knows that better than Sarah Tucker Price, M.D., Ph.D., who is part of an innovative new program rolling out this month from MUSC Health that provides in-house primary care services to patients at Hollings Cancer Center at the Medical University of South Carolina.

“Only a few cancer centers in the country offer similar programs,” she says. “I am excited to be a part of starting this clinic to expand the number of services available to our patients and to make Hollings Cancer Center more of a comprehensive medical home.”

The term “cancer exceptionalism” describes the tendency for a person with a cancer diagnosis to focus only on that. Price knows that this is a dangerous attitude and that many cancer patients enter treatment without having a primary care doctor. The idea of primary care being embedded into the cancer center allows easier access for patients to be able to schedule same-day appointments and use her as a resource for long-term care, short-term care or as needed.

Price explains that this “one-stop shop” concept can help streamline cancer patients’ care and limit the number of visits they need to make. It also helps to catch those with chronic medical issues who may be falling through the cracks. Cancer patients and survivors have specific care needs, Price says. “They often have nuanced care needs, depending on their diagnoses and treatments, which a cancer center has specialized resources to offer patients and for which primary care has an important role,” she says. “Certainly, it’s important to manage any medical issues that they have going into cancer diagnoses and treatments to give them their best opportunity to do well.”

For example, a patient with hypertension can be more at risk for cardiovascular complications from some chemotherapeutic agents. Patients with diabetes, especially when it’s uncontrolled, can find it negatively affects their cancer treatment.

“There are things that we can do to control blood pressure and control diabetes that can have a meaningful outcome, not just on decreasing the complications of diabetes and hypertension but also having a positive effect in terms of their cancer outcomes.”

As a physician, as well as a researcher with a background in oncology, Price has special insights into serving the needs of cancer patients. She knows that for them to be eligible to enroll in some clinical trials, they need to have their blood pressure controlled to receive certain therapies. “This
goes beyond clinical trials as well. I’ve had patients referred to me by their oncologists who couldn’t continue chemotherapy until their blood pressure was lowered.”

Then there are the other common issues for cancer patients that need to be addressed, from cardiotoxicities to depression and anxiety. “There are a number of issues that we can help patients manage. Anxiety, depression and insomnia, among other things, are common in cancer survivors. Deconditioning is common after undergoing certain cancer treatments for which individuals may benefit from physical therapy or additional home resources. Helping cancer survivors get referred to appropriate support services, including psychological support services, nutritional support and palliative care, is also incredibly important.”

Part of Price’s new role gives her easy access to oncologists and other specialists at Hollings Cancer Center, so she can help to coordinate and tailor care among multiple specialists. She likes working as part of a bigger team.

As a coach of a local soccer team, Price isn’t new to the concept of teamwork. She grew up playing ice hockey and played lacrosse at Yale University. From there, she came to MUSC to earn her M.D./Ph.D., studying cancer research and specializing in the field of family medicine. In this dual role, she gets to blend the two areas of expertise she is most passionate about.

“I think cancer research is important and affects so many people in a very dramatic way,” Price says. “I think there’s a lot of potential and opportunity to give people more quality time if we can better understand what drives cancer development and growth. We also need to make sure we are providing the best quality care to patients during and after treatment.”

Price will work out of Hollings Cancer Center on Mondays, Wednesdays and Fridays. With time dedicated to research, Price also will be focusing on opportunities within primary care to improve cancer survivorship care. Another aspect that is often forgotten is a patient’s transition to life after cancer treatments have ended, Price says. She wants to support patients as they cope with what may be lingering side effects after cancer treatments and help them map out smooth transitions into survivorship.

“Communication following transition from active treatment is critical to make sure individuals receive recommended surveillance and screening, including screening for other cancers. This transition is an area where gaps in care often occur and for which communication with all members of the patient’s care team is essential,” she says.

It’s an area ripe for research. The Institute of Medicine’s report “From Cancer Patient to Cancer Survivor: Lost in Transition” has set four components of survivorship care, including better coordination between specialists and primary care providers. Improving cancer survivorship care is especially important with the number of cancer survivors projected to increase by 29.1% to 21.7 million by 2029, according to the National Cancer Institute.

Price is glad to see that there’s more focus on serving the needs of cancer patients and survivors, given the complexity of their care. It’s why she chose clinical care rather than focusing solely on research, she says.

“If you’re a patient being seen at Hollings Cancer Center, we want to be able to support you in as many ways as possible, and primary care is an important aspect of that. We want to help make primary care as easy as possible for you to access for any needs that you might have during this challenging part of your life.”

For More
Ask your oncologist or nurse navigator for a referral or call 843-792-3451 to schedule an appointment with Dr. S. Tucker Price.
Dr. Katherine Sterba has dedicated her life’s work to helping patients transition to life after cancer.
After completing treatment, cancer survivors can face tremendous uncertainty about what life will be like after cancer.

No one knows that better than Katherine Sterba, Ph.D., a behavioral scientist at the Medical University of South Carolina and researcher in MUSC Hollings Cancer Center’s Cancer Control Program. She specializes in helping cancer survivors and their caregivers with care transitions after cancer.

With an aging population and advances in cancer treatment, the number of cancer survivors has increased dramatically in recent years and is projected to increase by 29.1%, to 21.7 million by 2029, according to the National Cancer Institute (NCI).

“The NCI’s Office of Cancer Survivorship defines survivorship as spanning from the moment of diagnosis through the rest of a patient’s life and includes caregivers, family and friends.

“Based on the complex and varied treatment types and potential toxicities our cancer survivors face, a one-size-fits-all approach won’t work, and we need to consider each individual survivor’s needs and create tailored programs,” she says. “My research focuses on developing interventions for delivery in the oncology setting at the end of treatment that are focused on survivors and family caregivers to help promote optimal recovery and better transitions in care from treatment to the post-treatment period.”

What her research has shown is that this can be a period where cancer survivors feel lost after leaving the safety net of care and may not know how to connect to the right support services. They may need links to a variety of different resources at this time, and research has not yet determined the best models for follow-up care for this growing population of survivors.
Because there are unanswered questions regarding the long-term effects of cancer treatments, it is hard to gauge how to optimize care for cancer survivors, 64% of whom are over the age of 65, Sterba says. Survivorship is a critical area of research, and caregivers are often an overlooked group.

According to the American Cancer Society, 40% of caregivers reported caregiving as emotionally difficult. The Cancer Caregiving in the U.S. report found cancer caregivers spend an average of 32.9 hours a week caring for their loved ones, with 32% providing 41 or more hours of care weekly, the equivalent of a full-time job.

“Caregivers take on challenges in caring for a loved one with cancer, and we have to stop and think about the toll this can take on caregivers,” she says. “Caregiving demands can involve emotional challenges and financial toxicities and may cause caregivers to overlook their own health.”

Many people aren’t aware of this toll, and when they find themselves in a caregiver’s role, feel they don’t know what to do. Sterba hopes to change that – in part by exploring how technology can assess and address needs. Her recent research, specifically designed for head and neck cancer survivors and their caregivers because of their nuanced care needs, includes studies involving three areas:

• Survivorship needs assessment.
• End-of-treatment care plans.
• A mobile resource app for caregivers.

End-of-treatment care planning is critical for head and neck cancer patients, she says. “These plans are really unique and different than survivorship care plans for other types of cancers,” Sterba says. “We sat down at the end of treatment with both survivors and caregivers, marking the transition from treatment to the post-treatment period.”

In a 45-minute meeting, they provided care plans to the survivors that outlined their diagnoses and treatment and follow-up care plans along with information concerning symptoms to watch moving forward, potential adverse treatment effects and health promotion recommendations such as smoking cessation, healthy diets and physical activity.

In a complementary study, Sterba and other researchers developed a survivorship needs assessment planning tool they call SNAP to assess needs at the end of treatment in head and neck cancer patients and caregivers.

“We have developed a survivorship care planning tool that is a quick needs assessment to try to speed things up and get right to the family’s immediate concerns,” she says. “Survivors receive the care plans along with a set of messages and referrals to try to help meet their current needs, address any barriers to follow-up care and link them with supportive care referrals and other resources over time.”

Before their survivorship visit, patients and caregivers are given tablets to fill out brief assessments that take six minutes for caregivers and 11 minutes for patients to complete, she says. Based on the responses, tailored care plans are generated to help to address the most pressing concerns, issues, symptoms and health behaviors.

Megan Scallion, a social worker at MUSC and program coordinator on the study, says meeting with the patients and caregivers was often emotional. One aspect she likes about the study is how it includes caregivers, who often carry a heavy load of stress.

“Caregivers sometimes became emotional in discussions of their roles during their loved ones’ treatment and recovery. The care they provide during these time periods is demanding and may cause caregivers to overlook their own personal needs,” she says.

Just going over the plan was therapeutic. “Reviewing the care plans allowed time and space for caregivers to recognize their efforts and give themselves permission to focus more
on their own needs now that their loved ones are in the long-term recovery phase,” she says.

In addition to implementing survivorship care plans into head and neck cancer post-treatment routine, health professionals have developed a template that could be uploaded into patients’ electronic medical records so nurses and doctors can generate the care plans that are in line with guidelines from the Commission on Cancer.

SNAP has helped doctors like Evan Graboyes, M.D., a Hollings Cancer Center head and neck oncologic surgeon-scientist, identify the specific needs of each survivor and caregiver.

“SNAP helps me offer personalized care that addresses the aspects of survivorship care that matter to patients and their caregivers without wasting their time, money or energy on other aspects of their survivorship care that aren’t as relevant or important,” Graboyes says. “Because SNAP is comprehensively mapped to all domains of survivorship care, I know that I am not missing anything for my patients and caregivers.”

Sterba also is exploring how to develop an app specifically for caregivers of head and neck cancer patients. “The app is focused on sending caregivers home at the end of radiation therapy with tools, resources and encouragement about being a caregiver,” she says.

The app is in reaction to findings from the previous two studies. Caregivers had voiced their concerns about needing interventions to take home with them at the end of treatment.

“Our caregivers end up doing a lot of medical tasks and nursing tasks,” Sterba says. “Their lives really change.” The app will give caregivers tools to help to transition into survivorship and manage stress, providing resources such as encouraging videos, practical tips, relaxation exercises and easy recipes.

While this intervention work is exciting, it is also important to study how to get promising interventions that have been developed for cancer caregivers into the clinic, she says.

Sterba also is leading a current study in partnership with Wake Forest University that is scanning cancer centers around the country to evaluate their practices for identifying and assessing needs in cancer caregivers and to evaluate the availability and delivery of services for caregivers in the oncology setting. Findings will be used to guide the development of system-level interventions to help cancer centers deliver supportive care resources to caregivers who need them.

“We really want to see what’s going on out there so we can figure out the best ways to get good programs into the hands of those who need them,” Sterba says. “I hope these interventions can be disseminated widely.”

Sterba hopes to see her survivorship research and technologies scaled up further and implemented into practice, she says. Survivorship resources could help patients get through the early recovery period faster and avoid poor outcomes such as adverse long-term treatment effects and unplanned health care visits or hospitalizations.

Cancer survivors are the most courageous people I know, and while the advances we have made in treatment are amazing, we have a commitment to assist our survivors and their caregivers to help them reach their best quality of life after cancer.”

- Dr. Katherine Sterba
I feel like I’m Alice falling through the hole, trying to grasp onto something, and there’s nothing to hold on to.”

- Christy Crouch
Cancer can do a mind job on someone.

No one knows that better than Christy Crouch. In 2015, the therapist lived in Kentucky. She volunteered at concession stands for her daughters’ school, planned school events and attended church activities. She loved teaching psychology at the college level and serving as a guidance counselor at a small Christian school.

But that all changed the night of May 22, 2015, when Crouch had a massive seizure. The incident led to her finding out that she had a brain tumor at just 47 years old.

“I feel like I’m Alice falling through the hole, trying to grasp onto something, and there’s nothing to hold on to,” Crouch says.

Many aspects of her life changed dramatically and left her in physical and emotional need of help. Her jobs, her balance, her memory – all taken from her by her disease. When she moved to Charleston in 2016, she was relieved to learn Hollings Cancer Center had many support services, including psychological consults.

That’s when she met Wendy Balliet, Ph.D., a psychologist with Hollings Cancer Center who specializes in cancer counseling. She helps Crouch find her bearings when she feels she’s falling down that tunnel.

“Dr. Balliet has been probably one of the biggest contributions to my sense of purpose and sense of healing,” Crouch says. “She helps me look at those things that I can hold on to.”
The Tumor
After the shock faded about her diagnosis, Crouch had to figure out what living with cancer meant. The MRI after her seizure had revealed devastating news. A brain tumor, later identified as a grade two oligodendroglioma, sat on Crouch’s parietal lobe. This rare type of tumor makes up only 4% of all brain tumors. It was more than her doctors in Kentucky could handle, so she was sent to Duke University.

Before brain surgery at Duke on Sept. 14, 2015, Crouch had one request for her doctors.

“I said, ‘You need to understand – the most important thing about me is my husband is deaf. I need one eye and one hand, or I have nothing to live for.’”

She awoke unable to move her left side and immediately started to practice signing with her right hand to help her left hand remember how to sign. After a month of rehabilitation, Crouch returned home feeling as though the tumor had stolen her independence – she couldn’t drive, was constantly exhausted from her seizure medication, couldn’t be as involved in her three teenage girls’ lives and had to quit her two beloved jobs. She questioned if her life would ever be filled with the joy she once knew.

Then, her family was dealt another devastating blow – her husband was losing his job of 25 years. Finally, nine months later, a difficult period in their lives turned triumphant when her husband found a job in Charleston.

“When we found out we were moving here, I knew that I had every resource that I needed within 30 minutes,” Crouch says. “That was a huge comfort to me.”

Crouch was filled with relief when she found out that Hollings Cancer Center had a brain tumor board.

After moving to Charleston the day after Christmas in 2016, she came under the care of neurooncologist Scott Lindhorst, M.D., at Hollings Cancer Center.

“I felt even better knowing that Dr. Lindhorst was trained under my doctors at Duke and the communication between them has been phenomenal,” Crouch says. “He’s amazing.”

A New Reality
Even with the best care, Crouch’s surgery left her with disabilities and a new reality. She dwelled on her old life – a time when she had a strong memory and could master any puzzle and multitask at work and home. Now, she scribbles important details, conversations and events she needs to remember into a notebook and is still learning how to walk again.

“Because of my problems with proprioception, I have no idea where my left hand or foot are if I’m not looking at them,” she says. “I’ve broken my toes so many times, it’s not even funny.”

After having to leave her jobs, Crouch had a hard time finding activities practical enough for her new way of life. Through counseling, she’s learning to celebrate the small things, like driving, finishing a book and knitting a dishcloth.

“I’m the happiest girl when I’ve got a book in my hand, and I actually remember what I read,” she says.

With every mile driven, page read and stitch knitted, she regains a little piece of joy. If her diagnosis opened her eyes to anything, it’s to be more present. Whether it’s paying attention to where her foot is or spending time with her husband and daughters, she wants to live in the here and now.

“Never did I take the time to stop and go make those memories,” she says.
“because I didn’t realize I was going to be in this situation.”

She and her husband had long dreamed about their 25th anniversary trip. This year, they’ll make it a reality by going to Hawaii, giving them much-needed time together.

In 2018, Crouch’s “word of the year” was purpose. This year, she chose perseverance. Little did she know how fitting the word would be.

Upon her return to Charleston from the trip, she will begin radiation and chemotherapy. In March, they discovered the tumor had grown. Not wanting to endure more physical and mental limitations before her trip, her doctors supported her request to wait until after Hawaii to start treatment.

Resources, such as counselors and support groups, have given Crouch the support she needs to deal with how cancer has affected her life. Without Balliet, Crouch says she would still be needlessly struggling, as many other patients are, due to a failure to take advantage of such resources.

“I think we get so lost in the here and now and how bad it is that we forget that there are good things,” she says. “And that’s always been kind of one of my themes of life — to be grateful for everything.”

Through counseling with Balliet, Crouch has overcome her reluctance to ask for help. As her father-in-law told her, don’t steal other people’s ability to be a blessing by denying their help. She’s learned to place some of her burden on others and plan her life around what she can realistically do and chooses to do.

“I have to let go of being so self-reliant in that control and saying I need help,” Crouch says. “That’s why I’m so grateful that I have MUSC because, regardless of what I’ve needed, it’s been here.”

When she left her jobs, she thought she left her purpose with them. Attending brain tumor support groups has led her to find meaning in everything she does. She also has returned to her former role as a nurturer and caregiver. Using her trials and experiences, Crouch wants to counsel other patients, caregivers, friends and family who know the pain of a brain tumor diagnosis.

“If there’s a purpose for me going through all this to be able to help other people, then that’s what I have to do,” she says.

Through her cancer experience and therapy sessions, there is one thing Crouch has found she can always hold on to — hope.

“If you can hold on to hope, regardless of whether it’s little or big, that’s that something that I’m looking for to hold on to when falling through that tunnel,” she says.
A SARCOMA SURVIVOR’S JOURNEY

Author
Advocate
Five years cancer free
No one wants cancer. Thom Schmenk sure didn’t.

But he turned an otherwise negative situation into a meaningful experience, authoring two books, celebrating a five-year cancer free anniversary and raising money for Hollings Cancer Center’s sarcoma research at the Medical University of South Carolina.

Schmenk’s journey began the day he retired in October 2012. His first stop? Walmart, to buy a bike.

“I just thought now that I’m retired, turn up the fitness a little bit and ride a couple days a week,” he says. “Well, a couple days a week turned into four or five days a week. And riding around turned into doing two to three to four to five miles.”

In the middle of enjoying his first summer of retirement, he noticed a new feature on his leg.

“This golf ball-sized lump shows up on the side of my hamstring,” Schmenk says. “I ignored it for a while. And then it started getting kind of sore to the touch.”

Thinking it was a result of his new hobby, he sought out his first medical opinion – from a bike shop employee, he says, laughing. Schmenk thought maybe the lump was caused by his bike seat. He used it as an excuse to get a new bike saddle, but when that didn’t solve the problem, Schmenk had to give in and go see his primary care doctor.
He was told it probably was a pulled muscle, to ice it and come back in two weeks. Two weeks passed, and the lump persisted, so the physician told him to trade ice with heat.

“Well, when I put hot on it, it lit up,” Schmenk says. “It turned all sorts of colors, and it got bigger.”

He was referred to an orthopedist from a nearby hospital system and waited two weeks to get an appointment. The orthopedist ordered an ultrasound, which took another week. It showed nothing.

“By now, it’s getting bigger. And it’s getting uglier. And it’s getting sore,” Schmenk says.

It was October when the doctor finally ordered an MRI. The “C-word” popped into Schmenk’s head when a nurse handed him three copies of his MRI instead of one. Back to the orthopedist he went with a copy in hand.

“He throws in the DVD, looks at it and says, ‘That’s a sarcoma,’” Schmenk recalls. “He says, ‘You’re in big trouble.’"

He was referred to Lee Leddy, M.D., an orthopedic surgeon at Hollings Cancer Center and now chair of the MUSC Department of Orthopaedics and Physical Medicine. The doctor was booked solid, but Schmenk was desperate to get some answers. Leddy’s office managed to fit him in the Tuesday of Thanksgiving week.

When Leddy came into the exam room, he did one of his signature moves. He rolled out the paper on the exam table and began drawing to explain what Schmenk had and the options to treat it.

“He’s laying out this battle plan on the paper,” Schmenk says. “We’re going to do a biopsy up and down that muscle and see what’s going on.”

Schmenk waited anxiously for the results. After what felt like forever, his phone rang. On the other line was Leddy with news that would change Schmenk’s life. “He says, ‘There’s no way to sugarcoat this,’” Schmenk remembers of the phone call. “He says, ‘It’s definitely leiomyosarcoma.’"

Leiomyosarcoma is a malignant soft tissue sarcoma found in smooth muscle tissue. It is one of the most common types of soft tissue sarcoma found in adults, according to the American Cancer Society. Five-year survival rates for soft tissue sarcoma patients range from 16% to 81%, depending on where the tumor is and if it has spread.

Leddy then brought in Jennifer Harper, M.D., a Hollings Cancer Center radiation oncologist. Schmenk recalls their first meeting.

“‘You could tell the woman was brilliant, but, at the same time, she never talked down to you,’” he says. “‘We didn’t leave there with any doubts. We knew exactly what we were up against.’"

He would endure radiation five days a week for six weeks. They would wait and see how it affected the sarcoma. Six weeks later, his leg, he said, had the “world’s worst sunburn.”

Next, Leddy performed surgery on March 5, 2014, right before Schmenk’s 64th birthday.

“I remember Leddy walking in after surgery, and he says, ‘You’re going to be cancer free for your birthday.’”

They removed his gracilis muscle, where the sarcoma was encapsulated. The sarcoma had reduced in size and was 90% cancer free. The other 10% no longer had the ability to metastasize.
“Leiomyosarcoma can be a very aggressive cancer, given the right circumstances. But given my circumstances, fortunately, it didn’t go anywhere,” Schmenk says.

For the first two years after his surgery, he would go back every 90 days for a checkup. That’s where he got the idea for the title of his first book – “Living Life 90 Days at a Time: A Sarcoma Survivor’s Journey.”

The book details Schmenk’s cancer story and gives tips to other cancer patients and survivors, which include:

• Have an advocate – they’re your clear mind.
• Try to understand people’s reactions – they might not always be what you expect.
• Get a second opinion.
• Stay positive, and surround yourself with positive people.
• Wake up glad that you’re still here.
• Have a goal, and try to accomplish something every day.

Now, he and his son, Todd, are working together to write a second book – “Being Team Positive: Building a Support Team for a Serious Diagnosis.”

“The book is designed that if your life is hit with a significant diagnosis, it explains what to do, what to say, what not to say,” Schmenk explains.

Even though it’s been five years since he heard the words “cancer free,” he thinks about his cancer daily.

What was really meaningful to her was that he asked how much of her time she spends trying to get funded, she says. “The fact he was able to understand how funding is a true barrier that impacts me as a researcher and the fact he was very excited to contribute to solving the financial problems that labs face was really awesome.”

Because sarcomas are so rare, Thaxton is the only sarcoma researcher at Hollings Cancer Center, which drives Schmenk to work hard to raise money for her work.

“When I see Dr. Thaxton’s face, the only word I can say is passionate,” Schmenk says. “She’s so passionate about this very narrow focus that she’s assumed.”

He has raised money by asking for donations and participating in sarcoma charity events like Swing for a Cure that recently raised $133,000. He also was the speaker at this year’s event, where the event committee surprised him with the Harper Drolet Award for his work in supporting sarcoma research. In the past, he felt uncomfortable attending the event, not wanting to flaunt his survivorship.

“I had a real hard time with it,” he says. “I’m trying to be happy, and there are all these people that are there because they lost somebody. You don’t talk about survivor’s guilt.”

But this year, Leddy wanted Schmenk to treat the event as his five-year cancer-free celebration.

“This five-year mark is my time to pay it forward,” he says. “What difference can we make going forward?”

Thom Schmenk and his wife know the importance of research and have dedicated their time to help support sarcoma charity events.

“This five-year mark is my time to pay it forward.”

- Thom Schmenk

“It’s kind of like driving down the road,” he says. “You can’t help but look in the rearview mirror and wonder if anything is catching up to you from behind.”

When Leddy called in November of 2013 with the results of his biopsy, Schmenk’s outlook on life changed. He wakes up every day with one mission in mind – defeating sarcoma.

“What am I going to do today to fight this damned disease? What email am I going to send? Who am I going to go encourage? How can I get somebody to donate $1? What did I do today? I’ve tried every day to do something.”

In March, Schmenk spent an afternoon with Jessica Thaxton, Ph.D., a Hollings Cancer Center researcher, in her lab that studies sarcomas.
Lung Cancer

Researchers received a $3 million grant from the National Cancer Institute to continue work on a novel immunotherapy combination to treat lung cancer.

The five-year grant supports research that began in 2016 when colleagues Mark Rubinstein, Ph.D., and John Wrangle, M.D., designed a phase 1 clinical trial that combined the checkpoint drug nivolumab and the immune stimulation drug ALT-803 to treat patients with lung cancer. The trial has since moved on to phase 2, looking at the effectiveness of this treatment.

“We are being given the opportunity to hone a therapy for patients who are going to respond to it. That’s a wonderful thing, and that’s what this grant allows us to study. It’s getting closer to personalizing who we offer this treatment to so that we have a greater expectation of a response to the treatment,” Wrangle says.

Cachexia

This study describes the generation of a new mouse model, called KPP, that could lead to a better understanding of the cachexia syndrome. This wasting condition, characterized by excessive weight loss due to muscle loss, has one of the highest incidences in pancreatic cancer patients.

Denis Guttridge, Ph.D., principal investigator of the study says, “We’re hoping that our new KPP mouse model will not only give us insights on how cachexia develops, but can also be useful as a tool for screening new anti-cachexia drugs.” Contributing to the study were Erin Talbert, Ph.D., who led the study, and Hollings collaborators, Maria Cuitino, DVM, Ph.D., Cynthia Timmers, Ph.D., Michael Ostrowski, Ph.D. and Gustavo Leone, Ph.D.

Cancer Growth

Addressing a long unanswered question of how cell division is controlled during development and normal maintenance in multicellular organisms, Gustavo Leone, Ph.D., and colleagues used animal models and applied deep learning tools to measure protein levels and expose cellular mechanisms that previously could only be estimated by cell culture systems. The findings begin to identify the possible early events associated with uncontrolled cell division, a key step in the early progression to cancer.

“Not knowing when and where ‘on and off’ switches for cell division are expressed is like having paint with no canvas. Now we have the canvas, and thus the cellular context, for how these proteins behave within cells in the body,” Leone says.

Dr. Guttridge

Dr. Leone

Dr. Rubinstein

Dr. Wrangle
Immunotherapy

Shikhar Mehrotra, Ph.D. and Xue-Zhong Yu, M.D., have discovered a way to improve immune-based treatments, such as adoptive T cell therapy and hematopoietic stem cell transplantation, by modulating T cells with thioredoxin, a powerful, naturally occurring antioxidant molecule. Two recent studies are published in the Journal of Clinical Investigation (JCI) and the Journal of Biological Chemistry (JBC) from these two long-term collaborators.

The study published in the JBC showed that thioredoxin extends the life of adoptive T cells by neutralizing toxic reactive oxygen molecules. According to the study published in the JCI, Yu says, “Thioredoxin is a natural product with no toxicity. We can use it to fine tune T cell activation in a way that will reduce graft-vs-host disease but maintain anti-tumor effect.”

Cancer Therapies

Besim Ogretmen, Ph.D., and a team of researchers who study lipid signaling in the context of cancer biology, examined the molecular details of the relationship between SET and PP2A and how the sphingolipid ceramide, a ubiquitous component of cell membranes and important signaling lipid, interacts with SET to regulate its function. Their results, published online on March 27, 2019, by The FASEB Journal, help clarify the molecular details of protein function, allowing researchers to develop better cancer therapeutics.

Breast Cancer

Breast cancer oncologist Antonio Giordano, M.D., Ph.D., recently received funding for research that has the potential to offer progress in the treatment of triple-negative breast cancer. Not only is triple-negative an aggressive type of cancer with a poor prognosis, but there is also a lack of targeted treatment options.

“The three projects we’re doing have the potential to offer progress in the treatment of triple-negative breast cancer. The common theme among these three specific aims is overcoming resistance in triple-negative breast cancer with novel drug combinations including the polo-like kinase 1 inhibitor onvansertib and immunotherapy.”
NCORP Site
MUSC recently received renewal as an NCORP Minority/Underserved (MU) Community Site. This $5.3 million grant will be used over six years to expand on previous cancer disparities research.

Chanita Hughes-Halbert, Ph.D., principal investigator and director of the Transdisciplinary Collaborative Center in Precision Medicine and Minority Men’s Health at MUSC Hollings Cancer Center, is thrilled with the news.

“We and our five partners at the VA and four community hospitals are gratified by the continuation of this program, so vital to the well-being of South Carolinians.”

The MUSC NCORP-MU program continues to have a significant and sustained impact with the aims of:

• Expanding the accrual of racial/ethnic minorities and medically underserved populations.

• Sharing expertise, knowledge and experiences with academic-community based partnerships.

• Assisting in the development and implementation of cancer disparities research.

“Particularly exciting in this latest iteration of the program are the increased emphasis on training clinical and translational researchers, and the chance to further build our collaboration and the statewide infrastructure for cancer control, diagnosis, therapy and the trials for all these phases of cancer prevention and care,” Hughes-Halbert says.

This program will continue to address the needs of medically underserved populations.

“An aspect of our plans for the upcoming award period that I’m enthused about is the prominence of cancer care delivery research in our ever-growing portfolio, and understanding in finer detail what constitutes quality care and its effects on cancer health outcomes.”

SC CaDRE
MUSC Hollings Cancer Center received more than $800,000 from the National Cancer Institute to support three new research projects that will be implemented under the auspices of the South Carolina Cancer Disparities Research Center, also known as SC CaDRE.

This initiative, which began in 2011, reflects the combined efforts of Hollings and South Carolina State University (SCSU). Together, this partnership has made significant advances in health disparities research.

Marvella Ford, Ph.D., associate director of Population Science and Cancer Disparities at MUSC Hollings Cancer Center and the SmartState endowed chair in prostate cancer disparities at SCSU, has been leading the SC CaDRE with Judith Salley-Guydon, chair of the Department of Biological and Physical Sciences at SCSU.

“We are really seeing the strength of the partnership. It’s already leading to new grants and new collaborations that wouldn’t have existed otherwise,” says Ford.

Funding will support three new research projects over the next three years. One project will focus on health disparities as it relates to heterogeneity of neuroendocrine cells in normal prostate and neuroendocrine prostate cancer and the role of NEUROG3 in the latter.

“The investigators previously evaluated the role of the microbiome in relation to rectal cancer, but now they’re applying their microbiome findings to prostate cancer,” says Ford. “So to me, that’s brilliance.”

The second project will develop deep learning and other artificial intelligence algorithms to assess environmental factors leading to cancer disparities in Sea Island/Gullah individuals using digital imagery and geographical information. The third project will evaluate the role of lipid metabolic pathways in breast cancer progression and disparities in African American and non-Hispanic white women.

“I think these are all creative projects. There’ve been a lot of studies, and we have to think outside the box and think about relationships between different types of cancer or between the environment and cancer as well as consider how we can intervene to reduce the high rates of cancer disparities and improve cancer-related health outcomes for the entire South Carolina population.”
Innovative Strategies Raising State’s HPV Vaccination Rates to Protect Children in the State

Picture the average South Carolina public high school, which has about 600 students. That’s close to the number of people in the state who get a cancer related to the human papillomavirus (HPV) each year.

To combat this public health problem, Hollings Cancer Center has launched a $700,000 three-year HPV initiative. Working in conjunction with numerous statewide partners including the South Carolina Cancer Alliance, the American Cancer Society and the S.C. Department of Health and Environmental Control, the cancer center has prioritized this as one of its top cancer prevention outreach projects.

Spearheading the campaign is Kathleen Cartmell, Ph.D., a public health researcher with Clemson University’s Department of Public Health Sciences, and Marvella Ford, Ph.D., the associate director of Population Science and Cancer Disparities at Hollings Cancer Center.

Cartmell says, “The HPV vaccine is extremely safe and effective, and it can dramatically help lower the number of HPV-related cancers, including cervical and anal cancers. There is an urgency right now to let parents and pediatricians know about their critical role in protecting children with the vaccine at an age when children’s immune systems offer the best protection.”

Hollings Cancer Center Director Gustavo Leone, Ph.D., says this is low-hanging fruit in cancer prevention. “I didn’t want us to look back and realize we could have done something – that we could have worked harder. This isn’t rocket science. This is something that is reachable. We can save lives with this vaccine.”

Efforts are beginning to pay off.

From 2016 to 2018, there has been a significant increase, over 10% for boys and 14% for girls, in HPV vaccination rates in South Carolina.

“*We’re so happy that the HPV vaccination rates continue to rise in South Carolina. We feel like this is due to the extraordinary efforts of a lot of state partners,*” says Cartmell. “It’s amazing what can happen when everybody works together to figure out how they could do their part to help solve a problem. And I believe that’s why our HPV vaccination rates are going to continue to rise each year in South Carolina.”

**Did You Know?**

- Human papillomavirus, or HPV, is a group of 150+ related viruses.
- HPV causes more than 30,000 cases of cancer each year.
- The HPV vaccine is recommended for boys and girls ages 11 to 12.
- If HPV vaccination is initiated prior to turning 15, only two doses of the vaccine are needed. However, if the vaccine series is started at age 15 or older, three doses of the HPV vaccine are needed.
- The vaccine protects against six types of HPV-related cancers, including most cervical and anal cancers and some cancers of the oropharynx, vulva, vagina and penis.

**For More**

Parents have the power to shape the future — they can prevent cancer by choosing HPV vaccination. Please join us in making South Carolina HPV cancer free. Follow the social media campaign on Facebook (HPVvaxSC) and Twitter @HPVvaxSC, and check out our new website at MUSChealth.org/HPV.
Vaping

With e-cigarettes more common than ever, researchers struggle to keep up with changes in the industry. It’s such a fast-growing trend, and there are many different types of devices on the market, says Matthew Carpenter, Ph.D., who is co-leader of the Cancer Control Program at MUSC Hollings Cancer Center.

While growing research suggests that e-cigarettes can help established adult smokers quit, there are at least two population trends that are causing concern, Carpenter says.

One is that the use of e-cigarettes among adolescents is increasing. The latest numbers show that the use of these devices has increased among teens and young adults. “These numbers are trending upward, and there is great concern that we could have a new generation of people addicted to nicotine. Under no circumstances should kids and nonsmokers use these devices.”

Second, recent incidents of pulmonary disease among people using e-devices raise concerns. “We do not yet know what is causing these incidents, since there isn’t one device or product that is common to all. Early evidence suggests that contaminants in the liquid, sometimes obtained from questionable sources, could be a factor. The CDC is a great source for the most recent information on these events.” Carpenter says, referring to the Centers for Disease Control and Prevention.

So where does this leave a smoker who is either using e-cigarettes or would like to?

All smokers should quit, by whatever means works for them. Combustible cigarette smoking kills half of all users. There are a number of FDA-approved cessation medications with solid evidence in support of that are both safe and effective, he says. E-cigarettes, though clearly not safe, are at least safer than cigarette smoking over the long term, for established smokers, he says.

Carpenter recommends smokers take advantage of smoking cessation services at the Hollings Cancer Center, led by Benjamin Toll, Ph.D. “It’s a great place for smokers to get the best, most up-to-date evidence and support to help them quit.”

For more information, call 843-792-9101 or visit hollingscancercenter.org/tobaccofree
THE COST OF SMOKING

STUDY CALCULATES COSTS ASSOCIATED WITH SMOKING BY PATIENTS WITH CANCER

A study released on April 5, 2019, in JAMA Network Open reported that smoking after a cancer diagnosis is associated with substantial additional costs of cancer treatment.

Researcher Graham Warren, M.D., Ph.D., says the study establishes a model to estimate the economic burden of smoking on cancer treatment, which is information that can benefit patients as well as health care providers.

“These data estimate that smoking could result in $3.4 billion in additional cancer treatment costs nationally if patients continue to smoke after being diagnosed with cancer,” says Warren, lead author on the study and professor and vice chairman for Research in Radiation Oncology at MUSC.

“We know that continued smoking can lead to bad treatment outcomes for patients with cancer. The 2014 Surgeon General’s Report concluded that continued smoking after a cancer diagnosis increases the risk of dying from cancer and other smoking-related diseases. This is really the first time that the economic burden of smoking on cancer treatment has been estimated.”

The authors analyzed how smoking decreased the effectiveness of cancer treatment and estimated how much it would cost to treat recurrence caused by smoking.

The study shows that continued smoking increases the risk of cancer treatment failure and that the average additional cancer treatment costs can approach $11,000 for each patient. Warren says these estimates are very likely conservative. “The study only focused on the cost of additional cancer treatment, but did not include the cost of treating side effects from smoking, such as increased cancer treatment toxicity or treatment of other smoking-related diseases such as heart disease, strokes and other diseases known to be caused by continued smoking.”

Warren says the study did not report on how smoking cessation would affect cost, but smoking cessation, even after a cancer diagnosis, is currently the best method health providers have to try and prevent the harmful effects of smoking on cancer treatment.

“The best decision a patient with cancer can make is to decide to quit smoking. The next step is to put resources into identifying the best treatment approach for all cancer patients, including those who smoke when they are diagnosed with cancer.”

Population Health Award
Graham Warren, M.D., Ph.D., was recently recognized during MUSC’s 2019 Faculty Convocation for his work in promoting smoking cessation to patients at Hollings Cancer Center and beyond. The MUSC Foundation Population Health Award is based on the recipient’s outstanding contributions that impact the health of the community.
As a child, Matt Prisby watched his father support local vendors selling apples and pencils on the sidewalk, despite his family’s own modest financial circumstances. As he grew older, he began to think about his father’s example and how he could give back and make a difference in his community.

His wife, Sheryl, a dental graduate of the Medical University of South Carolina, shared his passion for giving back. The couple also shared a love of golden retrievers. They rescued several and directed all of their philanthropic giving toward animals for many years. But when Sheryl died of cervical cancer in 2014, Matt knew he needed to honor his wife of 26 years in an impactful way.

Matt established the Sheryl Sirisky Prisby Scholarship in Gynecological Oncology, which is the first scholarship dedicated exclusively to the research of women’s cancers at MUSC Hollings Cancer Center. This scholarship was made possible by Matt, who not only gives annually, but who also has made a planned gift through his will to create a legacy for Sheryl. The latest recipient of Sheryl’s Scholarship is Hollings Cancer Center researcher Joseph Delaney, Ph.D., who is an assistant professor in the Department of Biochemistry and Molecular Biology. Delaney’s research, which targets ovarian cancer, uses a five-drug mixture called Combination of Autophagy Selective Therapeutics or COAST. His study will use mouse models to evaluate if his newly developed drug treatments can achieve complete remission in the mice without harming essential organs.

With these data, Dr. Delaney will be able to move to the next step to see if such a treatment can prove effective and safe in treating ovarian cancer in humans.

With a combination of annual and planned giving, Matt is making a difference in the fight against cancer now, and providing hope for the future.

“One hundred years from now, I hope I’m able to show people that anybody can make a difference,” Matt says.

He wants to encourage more people to give, no matter the amount, and to share their stories about what or who inspired them. “You really never know what’s going to resonate with people, and I think there needs to be more stories out there.”

**What Will Your Legacy Be?**

Matt is a great example of how you can implement “blended giving” to make an impact greater than you ever thought possible. He currently gives to Hollings Cancer Center annually, and he has set aside a gift in his will to further our mission in gynecological oncology at a greater level than is possible during his lifetime. To learn more about how you can change what’s possible at Hollings Cancer Center through a planned gift and annual giving, contact Debbie Bordeau at 843-792-7694.
Join Us for the 12th Annual Gourmet & Grapes

Experience A Dazzling Weekend at The Sanctuary with Visionaries from the Culinary World While Supporting the Hollings Cancer Center.

Thursday, January 30

**Gourmet & Grain**
A bourbon and BBQ mash-up

Friday, January 31

**An Epicurean Affair**
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Saturday, February 1

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Thank You, Charleston, For Voting Us One of the Best Foodie Events in Charleston!
José and Wendy Peréy are the friendly faces of Hollings Cancer Center who fill hungry stomachs and administer a daily dose of joy. Now, the Hollings Café owners will be supporting the cancer center they’ve called their second home for seven years in another way. They’ll be riding in LOWVELO, an outdoor bike ride on Nov. 2, 2019, in which 100% of rider-raised funds goes to cancer research.

And they’ll be doing it on a tandem bike for 25 miles.

The idea came about, oddly enough, because of car problems. Hollings Cancer Center Director Gustavo Leone, Ph.D., saw the Peréys’ car broken down after work one day and stopped to help. While waiting for other help to arrive, Wendy asked Leone about the bike ride they had seen promoted around the cancer center. The couple had a bike Wendy had been begging her husband to get rid of. But now, she had a better idea.

That’s when Wendy told José to get their tandem bike fixed – they were going to ride. The funny part? Wendy doesn’t know how to ride a bike.

“He’s the one pedaling,” she says with a laugh. “I just want to be a part of it.” And so does José. More than ever, he realizes the need for cancer research. Three years ago, he was diagnosed with chronic lymphocytic leukemia.

Now he takes oral chemotherapy to manage his cancer. On June 11, his lab results yielded very good news, and his prognosis remains positive.

“I think I’m the luckiest guy on the planet,” José says. “Here I am, diagnosed with cancer myself, and I get the best treatment from the best people in the world.”

José lives every day like it could be his last, as he thinks everyone should, and that’s by having fun and treating people with kindness. LOWVELO, he says, is just another way to do that.

“I think it’s great how Hollings participates in things to raise money for furthering cancer research,” he says.
“Anything I can do running a café to help that, being a cancer patient myself, makes me proud.”

As a team, José and Wendy like to brighten people’s days. The two met when José, a Charleston native and College of Charleston graduate, was working as a banker for South Carolina National. Wendy was managing her mother’s Chinese restaurant in the same shopping center. The women at his bank pushed José to ask Wendy out.

“She was way out of my league,” he says. “Still is.”

José nervously asked Wendy out. It has all worked out well as they celebrated their 31st anniversary on July 17.

“Some things you just know,” José says with a smile, referring to his wife. “Only thing I ever knew.”

The Peréys have been partners in life and in business ever since. They have two children and three grandchildren, with another grandchild on the way. Before taking over Hollings Café in May of 2012, they opened Charlie Steakery franchises, Wholly Cow ice cream shops, Majestic Grille and four Chinese restaurants in the Charleston area.

When the opening at Hollings Café came available, José and Wendy took over.

“Sometimes the direction finds you,” José says. “It was kind of fate.”

Now, the Peréys are icons at Hollings, drawing in people for not only their Friday egg rolls or daily specials but also the positive attitudes they radiate in a place that needs it the most.

“It’s good to be in a venue where people are giving back, and you really see how people are – not only the vulnerable part of them but the great part of them,” José says. “I’m very grateful and humbled by all of it – the whole existence.”

José is looking forward to participating in LOWVELO and seeing if his wife “really knows what 25 miles are.” But, to the Peréys, LOWVELO is more than a ride, just as the Hollings Café is more than a job.

“At this point in our lives, it’s a good way to give back,” José says. “We’ve seen so much in our time here, and it makes you appreciate how lucky you are.”
Mary Nell Goolsby knows how to take on a challenge. It’s why she decided to ride 50 miles just 10 months after an extensive surgery to treat her rare cancer.

Her son, Turner Waldrup, 26, and her brother, Lee Goolsby, 47, will ride double that.

LOWVELO means more to Mary Nell Goolsby than any bike ride ever has. The donations from the ride directly impact her life.

“Research is a really big deal to me right now, not just because I have cancer, but because I have a rare cancer,” Goolsby says. “I think we’re so fortunate that we have MUSC and Hollings here.”

Goolsby used to ride her Peloton bike for an hour a day, averaging 20 miles. In January, a cancer diagnosis brought her rides to a screeching halt.

She learned she’d have to have Whipple surgery, a procedure that involves removing the head of the pancreas, the beginning of the small intestine, a portion of the stomach, the gallbladder and the bile duct and reattaching the remaining organs to allow for normal digestion after surgery.

“My immediate response was I have to do this for my children. I have to go ahead and have the surgery,” Goolsby says. “Being told you’re going to have Whipple surgery after you learn about it is pretty scary.”

“William Lancaster, M.D., performed Goolsby’s Whipple surgery on Jan. 24 at MUSC. Goolsby felt strong after the surgery, standing and doing laps around the recovery floor, and didn’t have many of the common issues after the extensive surgery.

“I think a lot of that is the skill of Dr. Lancaster. I just cannot sing his praises enough,” Goolsby says. “I’m actually kind of proud of my Whipple scar. It will always remind me of what I went through.”

Post-surgery, Daniel Reuben, M.D., Goolsby’s oncologist at Hollings Cancer Center, changed her diagnosis from pancreatic cancer to stage 3 distal cholangiocarcinoma, also known as bile duct cancer. While the change in diagnosis was for the better, distal cholangiocarcinoma is rare, with little known about it. Goolsby couldn’t help but wonder – why her?

“When you receive a diagnosis like that, it’s like, what have I done? What could I have done differently in my life so that I wouldn’t have this?”

But Goolsby has learned the most important part to surviving cancer is staying positive. Even as she goes through eight rounds of oral chemotherapy, which caused her to temporarily lose her fingerprints, cancer has shown Goolsby who and what matters.

“You just realize how many friends you have and how important it is to make a positive impact on other people’s lives because before I didn’t see an expiration date anytime soon in my life,” Goolsby says.

One way she wants to make a positive impact is by participating in the inaugural LOWVELO bike ride with her family as her team, appropriately named the Whipple Warriors.

Training for the ride keeps her positive and engaged in a healthy lifestyle. “It’s something else to think about,” she says. “You have to wake up every day and have something to look forward to.”

While the 50-mile route seems intimidating, LOWVELO has given Goolsby positive momentum.

“I definitely want to enjoy my life right now while I can,” she says. “I can’t focus on the end. I want to focus on here and now and enjoy life.”
MUSC Hollings Cancer Center thanks the hundreds of riders and volunteers for making the inaugural year of its outdoor bike ride such a success!

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